

Developmental Disabilities Council  
Full Council Meeting  
October 18, 2013  
8:30 am to 12:30 noon

Location: Holiday Inn Yakima  
802 E Yakima Ave  
Yakima WA 98901

**Draft Minutes**

**Members Present:**

Diana Zottman, Chair, Aaron Morrow, Vice-Chair, George Adams, Helen Black, Josh Cutler, Leo Finnegan, Erin Gollehon, John Lemus, Maria Lerma, Rachel Nemhauser, Adrian Patayon, Teresa Payne, Joy Pendergrass, Jessica Renner, Laurene Rusing, Sue Searles, Jason Self, Janet Adams (DSHS-DDD), Sherrie Brown (UCED), Carol Miller (DOH), and Avereayl Jacobson (DSHS-DVR)

Staff: Ed Holen, Donna Patrick, David Maltman, Brian Dahl, Laurie Bahr, Linda West, Eva Rooks, and Crystal Diemert

Guests: Jackie McPhee, Executive Director of Children's Village;  
Yadira Galvin, Family Resource Center Director & Second Heart  
Second Hands Administrator  
Larissa Lavallee, DDC Intern

Support Staff: Chris Hardin and Kathy Easton

CART Transcriptionist: Monna J. McCormick

**Call to Order and Introductions**

The meeting was called to order by Vice Chair, Aaron Morrow and introductions were made.

**Agency Roundtable:**

**Yakima Resources - Jackie McPhee, Executive Director of Children's Village Yakima, Serving Children with Special Health Care Needs at <http://www.yakimachildreenvillage.org/who-we-are.asp>**

Jackie McPhee, Executive Director of Children's Village of Yakima came to present the Council with information on the unique program and services offered by her organization. Ms. McPhee has worked at Children's Village for 25 years and has seen it grow from a small program funded by the Department of Health to address the issues of children with special needs to a comprehensive agency that includes infant/toddler intervention, Parent-to-Parent, and medical specialty clinics. Through the clinics they are able to see over 1400 children a year and they have implemented an autism spectrum clinic that addresses the needs of families with children on the spectrum. The organization is unique for a rural area and for the number of comprehensive services offered. A full list of the services provided may be found at <http://www.yakimachildrenewillage.org/>.

**Yadira Galvan, Director of the Family Resource Center and Administrator of Second Heart Second Hands in Yakima at [www.frcwa.org](http://www.frcwa.org)**

Yadira Galvin is the director of the Family Resource Center, as well as the mother of three children with special needs. The Family Resource Center offers a wide range of services such as help navigating governmental systems like Social Security, help with developing Individual Education Plans for school age children and services for low income families for getting help with obtaining things like cell phones or accessing other community resources. Informational gatherings are a big part of the total activities provided by the Family Resource Center on topics as varied as Immigration Reform and autism education. Many of the people they serve are Hispanic immigrants, so it is not only the disability systems with which they need assistance. While not as big as Children's Village, the Family resource Center strives to make sure families have access to all the little pieces they need to live securely and happily.

**Welcome New Members –**

The Council is still waiting for the Governor to appoint the new Council members. This agenda item will be held over to the next meeting.

**Executive Director Report**

Community of Practice: Supporting Families over the Life Span – update  
Washington State was chosen as one of the five states to take part in this new initiative that will take a closer look at how families are supported as the dynamics within those families change. Currently the system is designed to support individuals living outside the family home but the

funding is not there so families are continuing to provide for their sons and daughters. As those individuals get older, their needs are different. The Kick-off is scheduled for November 5<sup>th</sup> and it is an opportunity for the state of Washington to identify issues, trends, and concerns as well as new models for doing things. If you did not receive an invitation, please contact Ed.

#### DDC Budget – update

The Council is on a 36 month cycle and the federal '12 budget started on the first of October 2011, and are available to use until September 30, 2014. The federal '13 dollars started October 1, 2012, and run until September 30th, 2015. Finally, fiscal '14 started on October 1st, 2013 and runs until September 30, 2016. Several people have asked over the last two weeks if the DDC will be affected by the federal shutdown? The answer is no, because right now, we are actively spending our federal '13 dollars until about April, where it will then shift to spending fiscal '14. Unlike Disability Rights Washington who had to shut down because their funding stopped; the DDC is a little more fortunate because our funding is on this cycle, and not limited by whether we receive funding on the first of October.

Laurie Bahr explained that the DDC's federal grant requires, with the only real restriction that affects planning is that there is a 30 percent cap on administrative costs, 70 percent for the state-funded activities. So you can see from '12, we overspent that a little bit to date, however, there's still 22,000 remaining in that grant year. Percentage-wise, we've planned at about 26 percent for admin, so we're within the only restriction. The remainder of spending will be contract obligations, which are under the state plan. Last July the Council approved the '13 spending plan and it has changed a little bit, due to the vacant position that was planned for so there are some anticipated savings until it's filled. The DDC started spending on the 2013 award July 1<sup>st</sup> and received a little bit more than the previous award year. It is anticipated that '14 might have some adjustments above the 1.278 million.

#### State Auditor's Report on DDC and follow up (Reading: 13-09)

The executive summary of the state auditor's report on the DD administration taps into a lot of important issues and challenges facing the administration. We have talked, from the advocate's perspective, to Secretary Quigley about the report as well as Evalyn Perez, Assistant

Secretary for the DD administration. There will also be a follow-up conversation with governor's staff, both Ted Sturdevant, policy chief for the governor, who is responsible for the legislative work for the governor and Andrew Smith, policy analyst, whose portfolio includes developmental disability, in a couple of weeks. Ed and Donna Patrick have also had an opportunity to speak with Representative Kagi about the report ; Representative Kagi is the Chair of the Early Learning and Human Services Committee, which is where the DD issues reside within the house of representatives. The full report is available on the state auditor's Web site <http://www.sao.wa.gov/AuditReports/AuditReportFiles/ar1009938.pdf>.

### Staffing

At the last Council meeting the Council voted to proceed to allow the Executive Director to hire an additional staff person to fill a vacant position with a new position, but that has since been denied by the Department of Commerce, who is arguing that the Council does not have enough indirect to support the position. This is a complicated argument that the Council thinks is incorrect. Diana Zottman and Ed have communicated to the Commerce that they think Commerce is mis-interpreting their own indirect agreement with the feds. If we are unable to get some relief at the departmental level, we are going to ask our federal funding agency to intervene on our behalf to try to help and correct Commerce's understanding. The position would be doing contracts, some state plan related things, some support to the endowment trust fund and so forth.

### Respite and Home Care Registry efforts

The Governor's office has put together a subcommittee to look into the issues around respite care and assisting families who experiencing barriers to finding respite providers. The small group have met a couple of times, with another meeting coming up in the next couple of weeks. One of the bigger issues is related to whether or not a respite worker really needs 75 hours of training, which is not required of any respite worker, to provide a few hours of supervision. The second issue is respite care different than personal care. A third issue is that there is supposed to be a registry out there where you can go and get connected with providers but that registry doesn't seem to be working very well, so we've had conversations with DSHS about fixing it and making it work better. We've had families that have gotten referrals from the regular industry, but when the workers find out that you're talking about a child, they do not have training. The subcommittee is looking at the issues and trying to come up with ideas that

would make it little easier for families to get access to providers and provide some more flexibility. Since the governor's office is kind of footing this initiative, it may be one step easier because it is not coming out of the agencies. Ed will keep the Council informed about how it transpires.

#### Managed Care Forum – David Maltman

There was a two-day forum September 26<sup>th</sup> and 27<sup>th</sup> on the subject of managed care for a developmental disability long-term services and support system. It was anticipated that the state will consider going to a managed care system for DD services. There are not really any clear indications, but everything that we see in terms of what's happening nationally and what Medicaid is doing looks like states are going to be asked to move to a managed care system. There were speakers from Wisconsin, Michigan, and Arizona. They all are a little bit different, however, these states have been doing managed care for people with developmental disabilities for the longest time. They're well studied and there's material around that allowed us to compare and contrast what we liked about the three systems and what we wanted to avoid. The second day, a speaker from the national association of state developmental disability directors explained why the developmental disabilities system is different than other kinds of healthcare or mental health systems that have been experiencing managed care. After which the participants had an opportunity to participate in a group process to discuss what they heard, liked, what steps would we have to take to implement a managed care system. There are videos of each of the speakers available on YouTube

#### **Council Member Exchange**

##### Access to Higher Education Task Force – Aaron Morrow

Aaron Morrow is the council's representative on this task force. The common goal of everyone involved is to open up college educations to everyone. They are in an information gathering phase right now and plan to have their first report to the Governor finished in December consisting of four points: first, make transition programs K through 12 to possible secondary education more seamless and successful. Second, review documentation on disability of postsecondary education institution, including developing a resource for how schools collaborate with family and students. Third, select a statewide method of best practices between K through 12 and postsecondary education and fourth, which I think is the most important is to create an outreach plan.

Ed Holen: Ed was involved in the drafting and writing of the legislation, and one of the things he learned, which was a huge challenge, is that you don't take much with you from the K-12 system into the college system. You almost don't even take your disability with you, from this perspective, that if you have to prove that you have any type of disability, the higher education institutions don't recognize anything that happened at the K-12 level. So if were documented as having a learning disability all of the way through high school, once you get out of high school into college, it's upon you to go pay for the testing that's needed to document that you have a learning disability, when the disability hasn't changed at all. Ed is glad that Aaron is on the documentation; that is one of the huge and expensive barriers.

Sherrie Brown: She believes the reason is because the Americans With Disabilities make it very clear that public or private higher education is not part of the right to education and so OCR and the Department of Justice has supported this idea that it is the responsibility of the student to provide the evaluation necessary to explain their impairment and what it is they need in terms of accommodations. Sherrie would like to argue that disability studies at the university and many other advocates around the country are working on colleges and universities to get them to do the ethically correct thing, which is to work with students and get them whatever they need to access the curriculum. But there is a very clear legal protection for higher education when they don't want to go there. suggestion is that to the extent Aaron ever has an opportunity to talk to the federal government, to talk to legislators about this very clear exception within ADA regulations and 504 regulations. Sherrie agrees there is no reason education can't do the ethically correct thing and follow the spirit of the law, but they're not obligated to legally.

#### No Paid Services – Sue Searles

Sue is part of the No Paid Services Caseload project that is continuing to work on educating the public and legislators and hopefully work on some new legislation in the upcoming session. There seems to be consensus that the group should ask for additional funding for family support and respite services in the supplemental session. In addition, this group talked about seeking funding to strengthen those peer networks. The thought was if they could strengthen Parent-To-Parent and some of these groups that are already in the community, then those people could help us with the no paid caseload and getting additional data for that. They are planning another meeting in December and then hopefully again in February. Sue is

very passionate about this effort because her son was on the no paid services list for almost nine years before they finally got services last year, and she understands the difference it can make in a family.

#### Disneyland Guest Service Pass- Laurene Rusing

The Disneyland Guest Service Pass was discontinued October 15<sup>th</sup> and Laurene recently signed a petition to reinstate the pass. If you would like the email, please contact Laurene Rusing. Helen Black said that it has been replaced with a system in which you go to a ride and check in and you are given a time in which you can return. Helen said it reduces the opportunity for exploitation; the reason the pass was discontinued. Sue Searles mentioned that the only concession is that you can only sign up for one ride at a time.

#### **Approval of July Minutes** Reading: 13-10

**MOTION:** Member Jason Self made a motion to approve the July Minutes as written, Member Adrian Patayon seconded the motion.

**PASSED** on a voice vote

**ABSTENTION:** Member Helen Black abstained.

#### **Adjustments to the Agenda**

None at this time.

#### **Chair's Remarks**

Diana thanked everyone that attended the Town Hall Meeting the night before, she thought it was very informative. She also wanted to thank Maria Lerma for dropping off the extra pizzas to the homeless shelter, it was greatly appreciated. Diana encouraged everyone to attend the legislative reception and let her or staff know if they need any sort of accommodation.

#### **Executive Session:** Executive Director Evaluation

The Chair excused everyone who was not a Council Member and the Council went into Executive Session to discuss the Executive Director's Evaluation.

The meeting was reconvened.

#### **Committee Reports**

Public Policy Committee, Helen Black

- Voted and passed a public policy work plan for 2014
- Discussed the supported decision making task force
- Created a legislative agenda for 2014
- John Lemus spoke to committee about his work around the parents with disability policy
- David gave a brief update on the federal government
- Established a schedule for Legislative calls beginning January 24th, if you haven't participated in a legislative call and you're interested, let us know and we'll make sure you get on that e-mail list.
- Legislative reception will be held January 22<sup>nd</sup>.

Membership and Governance Committee, Teresa Payne

- The council conducted a new chair training on Wednesday afternoon.
- It is likely we have new members by the next council meeting in January.
- The alumni group that we formed about a year ago will be coming back to report to the committee in January.
- Development Day - A sub group of our committee consisting of Erin, Aaron and John are working on an agenda for Development Day which will be held at the July 2014 on the Wednesday afternoon before the council meetings.
- Reviewed the attendance for the last year and found very few issues. The group decided how to deal with one or two small things having to do attendance and will respectively communicate with members who are have some difficulty attending on a regular basis.
- Talked about plans for recognizing the members who are leaving the Council at the January meeting.
- Reviewed and updated the big picture work plan to include items like reviewing and updating the Council charter and made suggestions for the January 2014 meeting.
- We are working on a new executive order because the old one is out of date. Diana and Ed are working with commerce hope to have more information at the next meeting.
- MOU, We also need a new memorandum of understanding because the old is also out of date. We hope to have a report for you in April.

**Workgroup Reports**

Self Determination and Leadership, Jason Self



- John Lemus spoke about the work that the Allies in Advocacy has been doing. The Allies are people from Self-Advocates of Washington, People First and SAIL who came together to create a statement on the civil rights of all people. If you are interested in seeing the statement please see Brian.
- John spoke about the Project of National Significance Grant awarded to Autistic Self-advocacy Network who is partnering with People First.
- Jessica Renner reported on the activities of SAIL. They are currently working on their legislative agenda. SAIL is also working with individuals and groups in Snohomish County and Kitsap County organize coffees for their local legislators.
- Aaron Morrow gave an update on the Higher Education Task Force on which he is the council's representative. The common goal of everyone involved is to open up college educations to everyone.
- Ed spoke about the Home and Community Based Waiver Quality Assurance Advisory Committee, the Communities of Practice Grant: Supporting Families over the Life Course, and the No Paid Services Caseload Part 2. These are all on going council activities.
- David Maltman came in and led a great discussion about the Taskforce on Alternative Decision Making. This is a group of people who are interested in strengthening options for people who are supporting people with disabilities without having to go into full guardianships.
- Went over the big picture work plan. The group scheduled dates to get reports from SAIL and other projects. They will also be looking more closely at the use of social media and other technologies and learn about advocacy efforts going on in Island Snohomish and Skagit Counties.

#### Community Supports and Services, Rachel Nemhauser

Rachel reported that there were no successful bidders on the Community Inclusion Project. The original proposal had been to target organizations outside the disability community to participate in and/or lead the project. The work group discussed the reasons around not having a successful bidder for the project. The work group explored more about identifying who has an interest in this issue. They determined that limiting the vision to a "non-disability" vision (for applicants) may have restricted disability-focused agencies with good ideas from the candidate pool. David Maltman proposed a new RFP that will focus on one contractor who will identify best

practices in inclusion, provide technical support and resources on inclusion and allocate seed money for a variety of organizations to work on community inclusion. Some of these groups will be new to community inclusion and some will be expanding their activities.

The workgroup voted to approve the Community Inclusion project with the stipulation that the contractor provide support to organizations at different stages of the inclusion process and that the work be shared with the Community of Practice project (as well as the Community Services and Supports Work Group).

In addition the work group reviewed its' workplan for FFY 2014 and discussed the January meeting agenda. The CS and S Work Group will discuss the housing needs for individuals with developmental disabilities who are living with aging parents at their January meeting.

### **Public Input**

John Lemus reported that People First was approached by the Autistic Self Advocacy Network earlier this year about partnering with their application to AIVD for a project of national significance around technical assistance for self advocacy. Ascend was awarded this project and they will be working together on this project. The DDC among the other self-advocacy organizations will be receiving a statewide inventory from the advocacy network to take inventory of self-advocacy organizations in our state.

### **Adjourn**

**MOTION:** Member Jason Self made a motion to adjourn the meeting and Member Helen Black seconded.

**PASSED** on a voice vote.

The meeting was adjourned at 11:41 a.m.

**Note: Materials are available in alternative format. Please contact the Council office at 1-800-634-4473.**